HISPC Phase 3: Kansas Rural Consumers Health Information Technology (HIT) Needs and Preference Summary Report

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Background

Consumer interests, preferences, knowledge and attitudes are central to successful health information exchange. As health information technology/health information exchange (HIT/HIE) in Kansas continues to expand and evolve, consumer understanding and trust in the process, especially technical and legal protections, are essential to successful outcomes.

It is believed that consumer education regarding HIT and HIE privacy and security issues and capabilities can facilitate HIT adoption, generate consumer advocates of HIT and HIE, and enable consumers to benefit sooner. Other research supports this logic model. The E-Health Initiative Foundation found that consumers were more receptive to the electronic exchange of their health information when they were better informed.[1]

Consumers create demand for information services and thus influence HIT and HIE through market forces. Consumers also recognize their need to acquire or define a vocabulary that will empower them to exercise the level of control that they demand over how their health information may be used by others. Some of this control will be exercised though contract (*i.e.*, through specific authorization and consent mechanisms); some through statute (*i.e.*, through consumer engagement in the process of legal reform).

Successful strategies for communicating these concepts require an intimate understanding of diverse local populations. For example, some individuals may be willing to learn about their HIE options only from their physicians. Some may be comfortable learning from peers, just as they might independently research their own medical conditions on the Internet. Still others might accept only programs with wide distribution or market acceptance.

The target audience for this project is the consumer in rural Kansas. The focus was chosen because Kansas is largely rural. Rural health care consumers have distinct educational needs regarding patient privacy and electronic health records which are different from their urban counterparts. These differences can be attributed to rural demographics and rural health care systems. In Kansas, 90% of all counties are characterized as rural, making Kansas one of the most rural states in the U.S. Further, 35% of the Kansas population lives in a rural county. Individuals living in rural settings tend to be older, sicker and poorer than those living in urban areas. Residents of rural areas face health care challenges that their urban counterparts do not, as

rural areas are typically medically underserved. For these reasons, the educational and outreach efforts for rural consumers are unique compared to those for urban health consumers.[2]

One of the issues that underlies rural and urban differences is demographics. In rural areas there are proportionately more elderly and they have more chronic health conditions. For example, recently described in a report by the Kansas non-profit advocacy organization, Thrive, in Allen County, 22.4% of residents (2000) are aged 60 and older; an estimated 66% are overweight or obese, and diabetes rates are 28% higher than the state average. Allen County is one of the locations for focus group meetings described in this report.

Another issue that underlies the differences between urban and rural health care is the structure of rural health care systems. In general, there are fewer providers and hospitals in rural areas and they operate with comparatively less financial resources. Rural people are more likely to be uninsured and have fewer health services available. Consequently, a larger proportion of rural residents obtain care in safety net community clinics as compared to urban residents.[3]

Rural health care consumers are also more likely to be economically disadvantaged than their urban counterparts. In Kansas rural and frontier counties combined, 32% of children live in poverty. [4] Among patients treated at safety net clinics, 92% live in family arrangements whose income is less than 200 percent of poverty and 56% are uninsured. [5] External economic forces can contribute to stresses not applicable to urban systems. Cyclical commodity prices contribute to regional income fluctuations. Rural businesses are generally smaller and often do not provide health insurance. Approximately one in five patients (19.5 percent) in rural Kansas communities is covered by Medicaid or HealthWave and about one in ten (10.5 percent) has Medicare coverage. Only 13 percent of patients seen in Kansas safety net clinics have private health insurance, and some of them may not be able to afford their deductibles and copayments. [6]

Migrant workers have additional unique educational needs as this group includes a relatively disadvantaged and mobile workforce. On average, hired farm workers are younger, less educated, more likely to be foreign-born and less likely to speak English. They also have additional barriers to access health care. [7]

In summary, rural health care consumers present unique educational needs associated with the demographics of rural communities and limited access to medical care. Across Kansas, rural inhabitants tend to be older, sicker and poorer than those living in urban areas. In addition,

nearly all rural areas are medically underserved. These factors combined create challenges which are unique to rural health care consumers and require focused, innovative approaches to obtaining health information, education and the health care services. While there are many related issues, this summary report focuses on the needs and preferences of rural Kansas consumers to guide education on privacy and security in the era of e-Health.

Project Goals and Purpose

The overall purpose of the HISPC III Kansas project is to educate consumers in rural Kansas on HIE and HIT privacy and security issues. The project began with this needs assessment and will conclude with the development of a toolkit that consists of materials useful for educating the Kansas target audience. A communication and evaluation plan will also be an outcome of the Kansas project. The deliverables from this project will be integrated into the multi-state Consumer Education and Engagement collaborative project.

The goal of the first phase of the Kansas consumer education and engagement project, was to identify and document diverse rural consumer's HIE/HIT privacy and security education needs and solicit feedback on preferences in regards to dissemination of messages and HIT/HIE issues. This was accomplished mainly through a review of the literature, an examination of other consumer education projects and an ongoing pilot study involving rural Kansas consumers in conjunction with another project that uses information technology for delivering consumer health information.

Methodology

Since HISPC funds did not allow for survey administration or focus groups, alternative approaches were applied to assess the needs and preferences of our target consumers in Kansas. We certainly encourage future scientific approaches, however, the information we obtained has provided a good starting point for the Kansas HISPC consumer education and engagement state project. To accomplish the goals for the first phase of the project, the Kansas consumer education and engagement HISPC team:

- Convened a representative consumer and stakeholder group to steer and advise the project, provide feedback on population subgroups to target, and schedule periodic meetings.

    - The steering committee (names listed at the end of this document) for the HISPC (phase 3) project met and served as the stakeholder group and provided feedback.
- Solicited feedback from consumers and stakeholders about their education needs and dissemination methods.
    - Individual consumers were reached for their opinion through focus groups and surveys conducted by the Kansas Health Online project - a healthcare cost and quality transparency web development project.
    - Feedback was solicited from individuals and organizations engaging consumers through personal health record training and applications.
- Engaged the leadership of the Kansas Area Health Education Centers, consumer education groups/educators, consumer representatives and others to facilitate and assist with reaching consumers and stakeholders.
    - An environmental scan identified efforts that involved the consumer.
    - The University of Kansas Area Health Education Centers (AHEC) are the primary educational outreach entities for the University of Kansas Medical Center (KUMC) and the principal means of decentralizing medical and other health profession's education throughout the state. The director of the AHECs was instrumental in assisting to provide access to consumers in S.E. Kansas through the Kansas Health Online project. Public librarians around the state were also recruited through the Kansas Health Online Project to assist with reaching consumers for focus groups.
- Collaborated with leading states who have targeted rural populations or have interest in this population, and other relevant partners to seek feedback on the rural consumer's HIE/HIT privacy and security educational needs, and preferred dissemination methods.
    - Outreach to other states with high rural populations such as West Virginia, Wyoming and North Dakota was completed, and materials were solicited and reviewed for this assessment. They were useful in guiding the questions we asked on the above mentioned surveys and focus groups. We also searched for literature and online resources that would inform the needs assessment.
- Consolidated and documented findings in this report.
- Solicited final feedback on the report from the Kansas steering committee.

- Finalized rural consumer needs and preferences document for submission to RTI.

Findings

The environmental scan revealed that few health information technology and health information exchange initiatives in Kansas engage or educate the consumer. Three innovative initiatives that engaged consumers are described here, including: an employer-based community health record provided by CareEntrust; AHIMA training program, and the health consumer web portal, *Kansas Health Online* provided by the Kansas Health Policy Authority. Individuals involved in these initiatives were contacted and provided useful information for this project.

CareEntrust, formerly known as Healthe Mid-America is a not-for-profit health information exchange organization based in the Kansas City metropolitan area. In 2007, CareEntrust received the eHI blueprint award for engaging consumers. The CareEntrust health record is accessible online, and is offered to consumers as a health benefit by sponsoring organizations. Conversations with CareEntrust staff revealed needs and preferences of the general Kansas consumer, emphasizing education on benefits of HIT, and education that addresses patient consent and use of sensitive information.

The American Health Information Management Association (AHIMA) is a national non-profit professional association that promotes effective management of personal health information needed for quality healthcare delivery. Members from the Kansas and Missouri chapters (KHIMA and MHIMA) attended AHIMA training sessions that prepared them to deliver a community-based presentation on how to better manage personal health information. They then volunteered to offer free public training to consumers in their communities. The audience was informed about how to access their medical records, their privacy rights and starting a personal health record. The KHIMA and MHIMA trainers shared the materials used for training and outreach, and emphasized the need for continued outreach, education and collaboration. The trainers identified areas that Kansas rural consumers could benefit from education. These included: continued education on the personal health record, patient rights, benefits and risks (privacy and security) of HIT and HIE. Trainers in Kansas and Missouri both observed that the practice of maintaining paper personal health records by older populations was common.

The Kansas Health Online project enabled us to get the individual consumer's perspective. The Kansas Health Online project team has developed a web portal aimed at health care cost and quality transparency. The web portal continues to be upgraded as a resource for Kansas consumers offering consumer health care tools, links and information. The web portal is being developed by the Kansas Health Policy Authority in partnership with other organizations such as the University of Kansas Medical Center library and the Kansas Health Consumer Coalition. To inform the project, over 20 consumer focus groups across the state of Kansas have been scheduled, many of them inclusive of rural consumers. Several of the initial focus groups were conducted in rural communities and participants responded to a brief survey that comprised of a wide range of questions. Some of the questions about HIT and HIE were added by the Kansas HISPC team at no cost. Responses from the focus groups discussions and surveys informed this needs assessment and results were comparable to national findings as demonstrated below. As the focus groups continue to be conducted across Kansas, the findings regarding HIT and HIE will continue to inform this project.

Materials were gathered from other states with large rural populations such as West Virginia, and online. These materials were useful guides for writing survey questions and questions to include in the Kansas Health Online focus group moderator guide. The following HIT questions were posed to the Kansas Health Online consumer focus group audience, and others were included in a survey completed by focus group participants after the focus group session:

- If you were provided with secure internet access to your medical record, would you use it?
- What do you see as the benefits and risks of having your medical record available through the Internet?
- What aspects of your medical record do you consider sensitive?
- Do you know what a personal health record is?
- Do you know what an electronic health record is?
- Would you be interested in a system that would allow you to have access to your medical records through the Internet?
- Would you give your doctor permission to share your electronic medical record with another doctor when needed for your medical care?

- Would you support or oppose an electronic prescription system where your doctor does not write down your prescription but securely sends it electronically to the pharmacy?
- Do you know whether your doctor keeps your medical record electronically or on paper or both? Electronically/paper/both/do not know
- How often do you see your doctor?

Literature reviews and online materials provided a broader national perspective for this phase of the project, some similar to our observations at the state level. Below we present some of the national findings that we believed to be comparable with state findings from the focus groups. Though this is a good starting point, the Kansas Health Online focus groups will continue throughout the year and these observations may change as we obtain additional input from rural consumers. Also, please note that the findings below include survey results as well as observations made during the focus group that may not be quantitative in nature. The comparable observations include:

- Deloitte Center for Health Solutions – 2008 Survey of 3000 Americans ages 18-75 found that 60% of consumers want physicians to provide online access to medical records and test results, and online appointment scheduling
    - In Kansas, 99% of the participants in the focus groups want access to their medical records online but emphasized the need for privacy and security. Some considered portions of their medical record sensitive and a minority thought all of their medical record was sensitive. When asked who they would give access to their sensitive health information, many said immediate family only and preferred to authorize access to anyone else. Several participants in the focus groups expressed their concern with health insurance company access to their records.
    - 73% of the focus group participants knew what an electronic health record was.
- Deloitte Center for Health Solutions – 2008 Survey of 3000 Americans ages 18-75 found that 1 in 4 consumers maintain a personal health record. Deloitte presented other findings to AHIC in the "Health care consumerism is a key theme in health system reform" presentation and found that 25% of consumers say they maintain some kind of personal health record. The majority use a paper-based system (84%), while nearly 30% use a computer-based system and 5% use a web-based system. A 2005 Markle

Foundation survey on attitudes of Americans regarding personal health records and nationwide electronic health information exchange showed that 6 out of 10 Americans support the creation of a secure online "personal health record" service that would allow consumers to: check and refill prescriptions, get results over the Internet, check for mistakes in your medical record, and conduct secure and private e-mail communication with your doctor or doctors. This survey also showed that 7 out of 10 Americans would actually use the personal health record.

  - 86% of the focus group participants in rural Kansas said they would be interested in a system that would allow them to have access to their medical records through the Internet.
  - Of the focus group participants in rural Kansas, 90% knew what a personal health record was. Four participants indicated that they were keeping a paper-based health record.
  - 95% of the focus group participants in rural Kansas said they would support a secure electronic prescription system.

- The 2006 eHealth Initiative consumer attitude and opinion research on secure electronic health information exchange found that support is extremely strong among consumers for secure electronic health information exchange with 70% of respondents favoring and 21% opposing its development. The 2005 Markle Foundation survey on attitudes of Americans regarding personal health records and nationwide electronic health information exchange showed that Americans believed an electronic exchange of health information would enhance quality and increase efficiency of health care system.
  - In rural Kansas, many patients travel to other towns to receive medical care. The support for secure electronic health information exchange to ensure availability of their health information across provider's offices was expressed.
  - 90% of the focus group participants said they would give their doctor permission to share their electronic medical record with another doctor when needed for their medical care.

- The 2006 eHealth Initiative consumer attitude and opinion research on secure electronic health information exchange found that overwhelmingly, the message that resonates

most for consumers is "having access to information in an emergency medical situation". Other messages that elicit positive response include those relating to "having access to your medical record when you are out of state", "having access to your medical record when you visit your doctor", and "having access during or after natural disasters."

  - In rural Kansas, consumer's sentiments supported this finding. Focus group participants from Coffeyville Kansas, for example, discussed the impact of last year's flood and were particularly interested in secure access to health information in a natural disaster. Several focus group participants shared their health status and many in need of a specialist travel to other towns for medical care. Longitudinal access to their health information by providers was viewed as critical. Portability of health information was proposed as a possible remedy to the problem that could occur if an individual's medical record was unavailable or the patient was too ill to communicate details needed to identify them in an emergency medical situation.

- The 2006 eHealth Initiative consumer attitude and opinion research on secure electronic health information exchange found that consumers overwhelmingly trust doctors the most (67 percent) to deliver them information about secure electronic health information exchange.
  - In rural Kansas, trust in doctors was very evident, with a focus group participant stating that her husband thought his physician was "God".

- The 2006 Blue Cross Blue Shield consumer's information preferences survey of 1647 members on Internet usage revealed that Internet usage for health information is significantly greater among women and higher healthcare users.
  - In one focus group a third of participants used the internet frequently to seek health information and all were heavy healthcare users.

- The 2005 Markle Foundation survey on attitudes of Americans regarding personal health records and nationwide electronic health information exchange showed that attributes of a proposed nationwide health information exchange that focus on security and privacy were rated as the highest priorities among survey respondents. The 2008 IOM's national survey on health research and privacy findings also showed that large majorities of the

public continue to hold and apply very strong privacy perspectives in the health area. A Harris Poll of 2,454 adults surveyed online in 2008 showed that nine million American adults believe that they or a family member have had confidential personal medical information either lost or stolen. When asked which medical records - computerized or paper - they believe may be lost or stolen most often, just under half (47%) think it is computerized records. About one in six (16%) think that paper records may be lost or stolen most often. Another quarter (23%) think that both computerized and paper records may be lost or stolen about equally.

- Focus groups participants in rural Kansas expressed privacy and security of their records as a major determinant of whether they would authorize use, and support sharing or automating of their medical records.
- Focus group participants in rural Kansas realized that privacy and security is as much of an issue for paper medical records as for electronic records. However, many believe the risks are higher for electronic medical records, with some worrying about identity theft and fraudulent use of records, as well as, unauthorized access of patient's medical records by health insurance companies.

Input was also solicited from individuals not involved in the focus groups, such as informatics experts in the state, those involved in application development for consumers, such as CareEntrust staff, public health staff, and those educating consumers on HIT-related matters such as the AHIMA staff. In summary, the following opinions were expressed:

- A resource center with useful HIT and HIE related materials that would be a central go-to location would be useful, and the toolkit developed through KS HISPC III would be a good starting point.
- Education on the protection of shared and maintained sensitive electronic health information was critical.
- For consumers to use personal health records, the value needed to be well communicated and convincing.
- Consumers needed to be better informed of their rights – such as patient consent and opt-in/opt-out rights.
- Privacy and security are of great concern to consumers in Kansas and those individuals and organizations that are engaging consumers.

- Communication of educational messages would need to be customized for different sub-groups in the rural population and well-thought.
- The use of health information for uses other than care, such as secondary uses (public health and research) and privacy and security considerations needed to be communicated to consumers. This was also supported by several participants in the Kansas Health Online focus groups who noted the value of electronic health records and health information exchange in research and public health, for example, specifically noting the benefits of using applications such as the state's interoperable immunization registry.
- Libraries, public health departments, and area health education centers (AHECs) were identified as places where consumers could be recruited and gathered.
- The Kansas Health Online and KAHIMA approaches and materials are possible models for consideration in the development of the KS HISPC toolkit, communication and evaluation plan.

Conclusions

The findings above were critical in providing future direction and focus for the Kansas HISCP III Consumer Education and Engagement project. Most importantly, this stage of the project identified areas of need and preferences that will better prepare us as we educate rural Kansas consumers on HIT and HIE privacy and security matters. We considered the findings and selected key education areas of need and preferences to pursue, including:

- Education on protection of health information as it is used for care and secondary uses, such as public health and research.
- Education to familiarize consumers on electronic personal health records and electronic health records, and e-prescribing; emphasizing the privacy and security controls, benefits/value, and risks.
- Education on patient's/consumer's rights.
- Education on the benefits and risks of health information exchange and participation in health information exchange (opt-in vs. opt-out).
- Education on patient consent issues.

- Education on electronic health information privacy and security controls and best practices.
- Education on federal and Kansas privacy and security statutes pertinent to HIT and HIE.
- Education on protections for sensitive health information such as mental health, alcohol and drug treatment, STD-related information, and genetic information. Preference for messages and tools tailored to target populations and accessible at a central location online.
- Preference for an evaluation to measure impact of education when the education is implemented.

Materials included in the KS HISPC consumer education and engagement toolkit will be gathered in alignment with these areas of need. The communication and evaluation plans will be developed in alignment with these areas of need and the relevant findings mentioned above.

Collaboration with ongoing and future consumer-related projects is a strategy the KS HISPC team plans to continue, and one that has benefited this project greatly. The Kansas Health Online project and others will continue to inform the consumer education and engagement project and vice versa.

References

1. Who do consumers trust to deliver information about health data exchanges? http://www.ihealthbeat.org/articles/2007/5/29/Who-Do-Consumers-Trust-to-Deliver-Information-About-Health-Data-Exchanges.aspx

2. What is Rural? USDA, http://www.ers.usda.gov/Briefing/Rurality/WhatIsRural/

3. Kansas Health Center Fact Sheet 2006, National Association of Community Health Centers, 2007, http://www.nachc.com/state-healthcare-data.cfm?State=KS

4. Kansas KIDS COUNT Data 2008, Kansas Action for Children, http://www.kac.org/kac.aspx?pgID=886

5. The Importance of the Health Care Sector to the Economy of Allen County Kansas Rural Health Options Project, October 2006, Kansas Rural Health Works, http://www.oznet.ksu.edu/krhw/reports/rural.html

6. Kansas Association for the Medically Underserved - White Paper 2008, kamu.org

7. Profile of Hired Farmworkers A 2008 Update, Economic Research Service July 2008 U.S. Department of Agriculture, http://www.ers.usda.gov/Publications/ERR60/

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